



Kent Community Health  
NHS Foundation Trust

# End of Life Strategy



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## Our end of life care strategy

This strategy provides direction to the trust in how end of life care (EOLC) should be provided regardless of service area or provider.

## Our mission

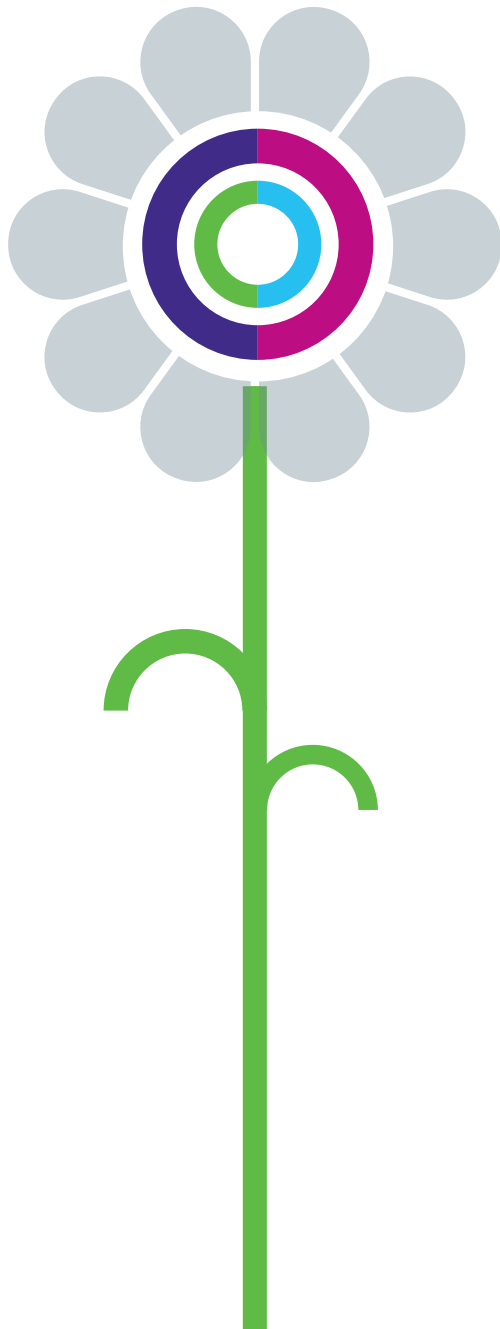
To work with our staff and partners to deliver excellent care to patients who are at the end of their life, so they can live comfortably and be supported to die in their place of choice.

Working alongside our partners, we will provide support and care to our patients, relatives, carers and others who are important to them.

## Our goals

- Provide high-quality care to people receiving end of life care.
- Work in partnership to establish and support preferences for individuals.
- Promote living well and as independently as possible.
- Support people who are important to each patient.
- Ensure equitable care to everyone at the end of their life.
- Work with specialist, acute and primary care providers to provide a seamless patient journey.
- Provide support to our staff.





## Strategy aim

Our first end of life strategy was launched in 2014. We feel now is the right time for it to be refreshed. Consultation with our staff and foundation trust members demonstrated strong support for a specific strategy for end of life care. It also provided valuable feedback about areas to focus on in the future, including learning from patient experience and the importance of including carers and valuing volunteers. We want to maintain the ethos of our first strategy, but feel our ambitions could be clearer and more focused.

This strategy provides direction to the trust in how end of life care (EOLC) should be provided regardless of service area or provider.

We aim to work with partners to address potential inequalities in care, to ensure delivery of high-quality patient care, regardless of why a person is approaching the end of their life. This may include adults and children with cancer, life limiting and degenerative conditions, dementia and frailty. Generally, this involves care given in the last year of life.

The strategy considers special groups, considered priority groups and encompasses the Equality Act

(2010) by taking into account the importance of eliminating discrimination and fostering good relations between different parts of the community.

End of life care provision is given in all settings; including a person's usual place of residence, such as their own home, nursing and residential care homes; also within our community hospitals, local hospices, and facilities providing short breaks and respite. People may transfer between care settings and this strategy supports development of consistent high-quality, individualised end of life care supported by collaboration of health and social care professionals/ organisations delivering the care.

# Background

Kent's population is currently more than 1.5million (2017). The biggest population growth is in the over-65 age group. This will result in a noticeable increase in demand for services providing care for long-term conditions and end of life care. Improving palliative and EOLC is an important element of the Sustainability and Transformation Partnership's (STP)\* priorities.

The trust recognises the need to support more people, including children to be cared for in the community and achieve dying at home, if that is their wish.

We understand age and other demographics is fundamental to delivering our healthcare service. The health needs of a population differ as the population ages. People from different ethnic cultures and backgrounds may experience barriers to healthcare, and have differing views on death and end of life care. The population of Kent is not uniform and Dartford and Gravesham have a more ethnically diverse population than other parts of the county. East Kent has a relatively young population, while the population of west Kent tends to be older. Vulnerable groups within our population include the homeless, migrant communities and travellers, people with disabilities and carers. We recognise there are areas of Kent, which are designated as having a more highly deprived population than other localities there are also new building developments, which all impact on the health and care needs of the population.

\* The Kent and Medway Sustainability Transformation Plan (STP) sets out how health and social care providers think services need to change to achieve the right care for people for decades to come. It is a partnership of between the NHS, Kent County Council and Medway Council.

The STP is work in progress. It describes what needs to be done differently to bring about better health and wellbeing, better standards of care and better use of staff and funds. Changes can only be implemented following a period of engagement and consultation with local communities in Kent and Medway.



## Goals

- Provide high-quality care to people receiving end of life care whenever needed, which includes achieving a good death.
- Work in partnership in care, where possible, to establish and support preferences for individualised end of life care.
- Promote living well and as independently as possible.
- Support people who are important to each patient.
- Ensure equitable care to everyone at the end of their life, regardless of their life-limiting condition, care setting, social circumstances, lifestyle choices, culture and religion.
- Work with specialist, acute and primary care providers to provide a seamless patient journey.
- Provide support to our staff following a complex or difficult end of life care situation.



# What is end of life care?

The terms end of life care and palliative care are used interchangeably by many people. End of life care is used more frequently since the Government released its end of life care strategy in 2008.

End of life care helps everyone with advanced, progressive, incurable illness to live as well as possible until they die.

It enables the supportive and palliative care needs of patients and those who are important to them to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.

## Our evidence base

There is a range of information available to guide organisations providing end of life care, including the NICE quality standard (QS) 13 for end of life care\*, last updated in March 2017. The focus of the QS covers all settings and services in which care is provided by health and social care staff to all adults approaching the end of life. This includes adults who die suddenly or after a very brief illness. Recognition is given to the needs of families and carers who may experience problems during this time. NICE QS 160 end of life care for infants, children and young people was published September 2017. This provides guidance for end of life care for infants, children and young people, (from birth to 18 years), who have a life-limiting condition that is expected to result in an early death for the person. The QS recognises the

need to support family members and carers and provides guidance on service goals. In 2016, the Care Quality Commission\*\* published a different ending: End of life care review, stating nationally that the quality of end of life care is variable.

The report demonstrated that inequalities in care continued to be faced by groups in our communities.

Our care plans reflect the Priorities for Care for the dying person (One Chance to Get it Right guidance DH 2014) focusing on five key priorities regardless of where a dying person is being cared for, whether this be a hospital, home, a care home or hospice. The priorities and ambitions have been embraced by the Trust and are the foundation of our care and treatment provision.

**The trust seeks to embed national guidance and has promoted the six ambitions for palliative and end of life care (NPEOLP 2015) as below:**

- 01 Each person is seen as an individual
- 02 Each person gets fair access to care
- 03 Maximising comfort and wellbeing
- 04 Care is co-ordinated
- 05 All staff are prepared to care
- 06 Each community is prepared to help

“  
*I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s).*  
”

\* NICE: The role of National Institute for Health and Care Excellence is to improve outcomes for people using the NHS and other public and social care services.

\*\* CQC: The Care Quality Commission is the independent regulator of health and social care in England.

# Infants, children and young people

The context of end of life care for infants, children and young people, includes people from birth to 18 who have a life threatening and/or life-limiting condition which is expected to result in an early death for the person. End of life care provision is often for longer, sometimes several years. This contrasts to the last year of life in adult end of life care. Similarly, end of life care for children from birth to 18 includes support for family members and carers.

Together For Short Lives advocates a care pathway approach, to ensure that families experience a co-ordinated approach to family-centred care throughout their child's life, regardless of their child's diagnosis, with clear and open communication and support to enable the family to build up and maintain access to an appropriate network of support, regardless of where they are cared for, whether that is in hospital, in their home, or in a children's hospice.

In east Kent, our specialist children's services provide community care to children who have life-limiting conditions and cancers. The east Kent team has a specialist oncology nurse who works alongside the Children's Nursing Team providing palliative and end of life care

for children and young people. Most patients receive shared care and access a number of providers, most frequently this is a specialist provider in London, the local acute hospital and our specialist children's community service. Paediatric services in west and north Kent are provided by the local acute trusts and infants, children and young people's hospice provider.

The Government Choice Commitment (2016) says that, to support high-quality personalised care for children and young people, commissioners and providers of services must prioritise children's palliative care in their strategic planning so that services can work together seamlessly and advanced care planning can be shared and acted upon.

**In 2017, NICE introduced a quality standard (QS160) that described six statements for national quality improvement.**

1. Infants, children and young people with a life-limiting condition and their parents or carers are involved in developing an advance care plan.
2. Infants, children and young people with a life-limiting condition have a named medical specialist who leads and co-ordinates their care.
3. Infants, children and young people with a life-limiting condition and their parents or carers are given information about emotional and psychological support, including how to access it.
4. Infants, children and young people with a life-limiting condition are cared for by a multidisciplinary team that includes members of the specialist paediatric palliative care team.
5. Parents or carers of infants, children and young people approaching the end of life are offered support for grief and loss when their child is nearing the end of their life and after their death.
6. Infants, children and young people approaching the end of life and being cared for at home have 24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care.

We have made sure the ethos of these statements are incorporated into our strategy.





## Achieving our goals

### **Provide high-quality care to people receiving end of life care whenever needed, which includes achieving a good death**

Our staff are passionate about end of life care provision and keen to make sure they meet the needs of patients and those who are important to them. We will continue to work with our partners, such as GPs, specialist palliative care providers and social care to deliver responsive community care.

We have implemented a champion role in all teams which care for patients who need end of life care. Champions provide a local point of expertise to clinical staff, attend regular workshops developing their knowledge and skills and cascade information. Within children and young people's services the specialist oncology nurse acts as the service champion for end of life care, attending workshops and training from tertiary centres.

Comprehensive training is available to clinical teams and ensuring staff have competencies is a fundamental part of this. For children's end of life, foundations of palliative care is available from tertiary centres at specific times of the year.

Paediatric nurses follow care delivery in line with Together for Short Lives guidance and national standards. They receive training and supervision from national centres of excellence in London.

We are continuously reviewing the standard of services provided to patients who received palliative or end of life care. There is continued development of the mortality surveillance review process of deaths in the community hospitals,

community patients and of patients with a learning disability. Policies supporting end of life care are accessible to staff; subject to review and updating.

We support patients to be cared for at home for as long as possible, and to die there if this is their wish. Our responsive care includes availability of prescriptions and medication to be given to maintain comfort and developing new processes to ensure medication accessibility. End of life patients often need specific additional equipment. To ensure the timely arrival of this, we monitor delivery issues with a fast resolution system in place. We will continue to review our service responses to make sure that end of life patients remain a priority and promptly receive visits.

Research is an integral part of our quality agenda. For end of life care this includes participation in research projects, such as, including carer support and care after death. This is something many patients want to do, to feel they can contribute to the health of others.

### **Work in partnership in care, where possible, to establish and support preferences for individualised end of life care**

Staff working in our community hospitals and patients' homes use effective care planning to support delivery of compassionate personalised end of life care. Recording known preferences and wishes in patients' records enables sharing and co-ordination of advanced and anticipatory care planning across services. KCHFT has developed a personalised care planning document, which is



left in the patient's home as a shared care document. This will be promoted in practice and continually developed.

Advance care planning with patients is a fundamental part of end of life care and we will continue to develop our workforce so we have the required confidence and skills.

Where people are no longer able to make decisions for themselves, we will ensure many decisions made on their behalf are in line with principles of Mental Capacity Act 2015. Access to advocacy and appropriate representation will be promoted.

To make sure patients and those important to them can be involved and supported in their care a range of information has been developed and we will continue to monitor this for relevance and effectiveness, reviewing with partners, as appropriate.

### **Promote living well and as independently as possible**

"Don't count the days. Make the days count" (Muhammad Ali). A key element of EOLC is enabling patients to get the best from every day they have. We provide multi-disciplinary care to support patients with clinical expertise that meets their individual needs.

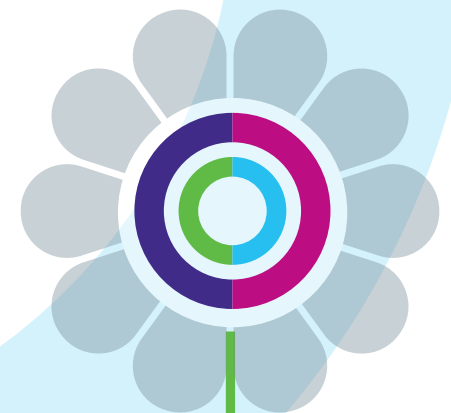
We work with organisational partners so each patient's wellbeing is supported by the most appropriate team. Care planning takes into account achievement of a patient's personal goals.

### **Support people who are important to each patient**

KCHFT holds regular events to increase public awareness of the importance of dying and making plans for the end of your life or a loved one's. We will continue to do this. We will collaborate with our partners, such as hospices, hospitals and other health and social care providers. We plan to develop our participation in national campaign weeks, for example, Dying Matters.

Carers' contribution to care is recognised independently from patient care and we extend our support to relatives, carers and those important to patients. Carers are involved in the care and our teams accommodate, where possible, their needs and preferences when planning patient care. Support for carers is essential and their right to referral for assessment of their needs is recognised; we aim to ensure appropriate referrals are made for carers' support to partner services. We will make training and information available about carer assessment and support services to staff.

Our teams extend their care to the relatives and carers after the patient has died. We send a sympathy card offering the option of further support. Our future plans include making our teams fully aware of bereavement risk assessment, so they can make referrals to appropriate agencies. In addition, we will seek to gain more patient and carer experience feedback to inform how services are planned and delivered.





**Ensure equitable care to everyone at the end of their life, regardless of their life-limiting condition, care setting, social circumstances, lifestyle choices, culture and religion**

Vulnerable groups in Kent include the homeless, migrant communities, people with disabilities and traveller populations. Our end of life care policy refers to special groups and work including:

**Learning disability**

KCHFT's Community Learning Disability Service provides dedicated support to people with complex needs. It is focused on reducing reliance on secondary services and acute admissions. The team is developing end of life care skills and support learning disability patients at home, hospital and residential settings. Our workforce has had initial training in caring for people with a learning disability at the end of their life to improve their knowledge, confidence and skills. More training will be developed and is tailored to the needs of people with a learning disability to achieve our end of life care strategic goals.

**Dementia**

KCHFT has a strategy for dementia, which encompasses end of life care. A key area is to ensure anticipatory care planning is used proactively with appropriate support materials. Our teams will have a working understanding of lasting power of attorney, advanced directives and respecting patients' dignity. Recognition of carer support and interaction with specialist partner organisations is essential.

**BME**

A report on end of life practices and palliative care among black and minority ethnic groups (BME) by Smith et al (2015) focussed on Kent and Medway-specific groups and recommended further training in cultural proficiency for healthcare professionals, the need for greater sensitivity around communication and targeted public health campaigns aimed at the general public and specific BME groups. In line with our strategic goals we will engage with service developments related to BME groups, promoting best practice and incorporating training, where relevant for end of life care. We will take advantage of opportunities to participate in promotional activities for this group of people.

**LBGT**

LBGT people experience significant barriers to getting palliative care when they need it; the publication Hiding who I am, the reality of end of life care for LBGT (Marie Curie 2017) highlights that many older LBGT people have significant fears about palliative and end of life care services. There is concern that service providers and health and social care professionals will be indifferent to their sexuality and gender identity and, in some cases, actively hostile. They worry palliative and end of life care services are not for them, or they will receive worse treatment than others. We are committed to providing equitable end of life care and want to diminish perceived barriers. Personalised care planning and engagement with advance care planning enables our teams to understand a person's preferences for care and focus on what is important to them. We will promote fair care for all.

### **Homelessness**

The needs of homeless people and end of life care are not well understood or met by regular health and social care services. This results in care and support becoming fragmented due to lack of continuity. End of life care for the homeless is challenging. Working in partnership with primary care partners will help us achieve improvements for homeless people. We will engage with patients, their families and carers through satisfaction surveys, as well as patient engagement events. We will continue to review every complaint, incident and concern relating to end of life care and ensure learning and is shared across our services.

### **Migrant communities**

These communities are recognised populations with a need for health and social care support. Within this group, no real assessment of potential end of life care needs has been established. Aid agencies report there are people who would benefit from palliative care. Working with partners locally, the need for end of life care can be responded to and initiatives developed in collaboration.

### **Gypsies and travellers**

These groups have poor access to healthcare. When they are in need of end of life care, there are additional cultural issues which make access difficult. We will be increasing cultural awareness with our staff around death, dying and bereavement, as well as promoting co-working with partners to increase engagement and service use.

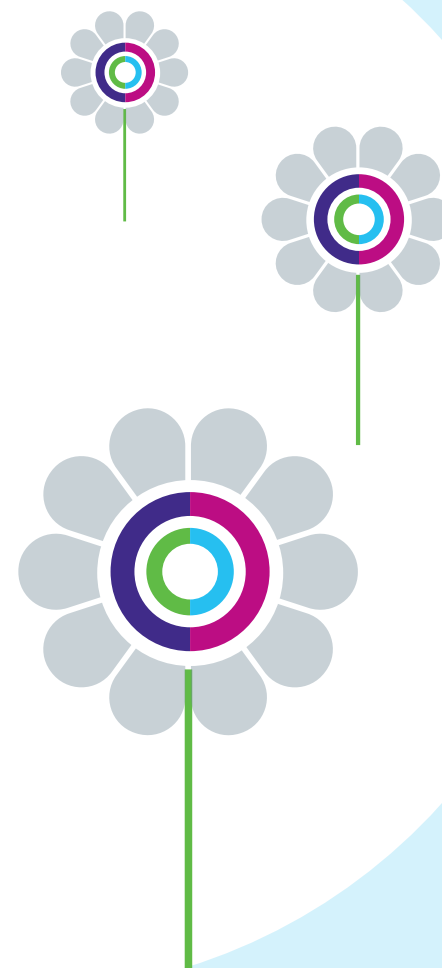
### **Work with specialist, acute and primary care providers to provide a seamless patient journey**

We want to make sure our patients have a good death and that care is delivered seamlessly and not dependent on the organisation that may be providing it. We will continue to work with our partners, including primary care, acute hospitals and hospices, to achieve this goal.

Our electronic patient record system enables us to share data between clinicians and, to some extent, with other providers. We will continue to develop this to allow timely access to patient information.

### **Provide support to our staff following a complex or difficult end of life care situation**

Our staff are important to us. To continue to deliver high-quality care, we want to make sure there is practical and emotional support. Involvement in end of life care can become intense when frequently looking after patients and those who are important to them. Staff support with a difficult death and time for debriefing/ reflection is an essential provision of management support. Additionally, the trust provides access to a confidential counselling service. We will continue to make sure end of life care education and training reflects the needs of staff.



## Next steps

There is a strong commitment to constant improvement of the care provided to our patients.

Our staff are passionate about making sure their patients have the most positive experience possible during end of life care.

We will strive to provide the best possible care to ensure end of life care continues to be a strong focus. Further quality improvement for the care of our patients, their families and their carers remains a priority.

# Strategy action plan

Goals	Actions	Lead	Expected outcome	Year		
				18/19	19/20	20/21
<b>Goal 1</b> <b>Provide high-quality care to people receiving end of life care</b>	Further development of the champion's role, increasing knowledge and skills. Increase our learning from patient and carer experience to influence improvements in care. Development of an increasingly responsive service. Supporting and staff to develop their communication skills.	EOL nurse consultant and community service directors Assistant director patient safety and experience Deputy chief nurse with service leads	Established local contact for expertise. New knowledge is cascaded. Improvements and changes to service are influenced by experience. Reduction in complaints about service response.	✓	✓	✓
<b>Goal 2</b> <b>Provide partnership in care, where possible, to establish and support preferences for individualised EOLC</b>	Enable staff to discuss advance care plans with confidence. All EOL patients have a personalised care plan.	EOL nurse consultant Heads of quality	Improvement in the number of people at EOL who have their wishes documented. Patients are engaged in the development of their care plan which reflects their preferences and wishes.	✓	✓	✓
<b>Goal 3</b> <b>Promote living well and as independently as possible</b>	Personalised care planning takes into account patient goals. Care planning demonstrates multi-disciplinary team referrals and working. Referrals are made to appropriate services. Psychological assessment is undertaken.	EOL nurse consultant EOL lead practitioner EOLC champions	Patients' need for wellbeing is recognised and supported. Referrals are made for appropriate support following assessment.	✓	✓	✓

Goals	Actions	Lead	Expected outcome	Year			
				18/19	19/20	20/21	
Goal 4	<b>Support people who are important to each patient</b>	Select and train volunteers to maximise capacity of those available to support patients at EOL and those who are important to them. Staff will identify bereavement risk factors.	EOL nurse consultant assistant director patient safety and experience EOL lead practitioner	A community that is supporting EOLC Those important to patients have their bereavements needs recognised and are appropriately referred.	✓	✓	✓
Goal 5	<b>Ensure equitable care to everyone at the end of their life. Regardless of their life-limiting condition, care setting, social circumstances, lifestyle choices, culture and religion</b>	Ensure all policy and resources related to EOLC embrace people with protected characteristics. Develop relevant EOLC staff training for supporting identified special groups, such as LD, dementia and BME.	EOL nurse consultant EOL lead practitioner EOLC champions	Equitable care is demonstrated Staff develop appropriate awareness and confidence.	✓	✓	✓
Goal 6	<b>To work with specialist, acute and primary care providers to provide a seamless patient journey</b>	Engage with EOL networks across Kent, driving development of these where there are gaps and when appropriate. Develop strong working relationships with those involved in the patient pathway (inclusive of specialist EOL care providers).	EOL nurse consultant EOL lead practitioner EOLC champions	Demonstrate partnership and collaborative working. Development of services to respond to patient and carers needs.	✓	✓	✓
Goal 7	<b>Provide support to our staff following a complex or difficult EOL care situation</b>	Engage with operations managers and team leaders to recognise staff groups requiring support. Feedback to EOL strategy group.	EOL nurse consultant EOL lead practitioner	Demonstrate identification of situations where staff required support. Provision of supported reflection and debriefing for staff.	✓	✓	✓





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 In everything we do, we care 